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HUMAN GENOME DIVERSITY PROJECT

The Human Genome Diversity Project (HGDP) was a scientific consortium organized in the 1990s with the goal of collecting DNA from indigenous peoples of the world. It failed to gain the US federal funding it sought principally because of its reluctance and inability to grapple adequately with the social, political, and ethical issues it raised.

HISTORY AND ORIGINS

The HGDP was first proposed by five geneticists, led by Luca Cavalli-Sforza of Stanford University, in a 1991 article in the journal *Genomics* and was almost immediately publicized in a four-page news feature in *Science*, the leading science journal in the United States. Where had it come from? Two scientific projects made the HGDP conceivable. These were (1) the success of the Human Genome Project in arousing public interest and funding for a large program in genetics and (2) the availability and precedent of collecting blood from indigenous peoples as scientific objects.

Blood had indeed been a staple of anthropological collection as early as the 1920s, following the first blood-group studies, from the standpoint of helping to assess the racial affinities of indigenous peoples. Although early geneticists, such as William C. Boyd (1963), had made blood studies a respectable and normative part of anthropological collecting, there was a long and tense history of attempts to make scholarly sense of the genetic patterns they produced. In the most glaring example, serological studies until 1972 had consistently reinforced the division of the human species into a few large, natural divisions, that is, races. But Richard C. Lewontin's (1972) classic analysis of human genetic variation showed instead that race was not in fact a major pattern of the human gene pool and that earlier generations of human geneticists had been finding and analyzing patterns that were not actually present.

By 1990 the Human Genome Project had established itself as "big science" for medical genetics, accompanied by hyperbolic prose about the need to undertake the project, principally to cure genetic disease. The biomedical model behind sequencing the human genome, however, neglected the fact that there is no "single" human genome. One could in principle sequence the normal modal variant for each gene—that is to say, the allele that does not give a person cystic fibrosis or Tay-Sachs disease or sickle cell anemia—and that presumably nearly everyone has the same copy of, for these genetic diseases are rare. On the contrary, what of the blood groups, in which the three major alleles—A, B, and O—are all normal? Clearly, given our knowledge of natural patterns of genetic variation, one would have to work with a much broader definition of *normal* than the Human Genome Project implied (Walsh and Marks 1986).

The HGDP, then, sought to solve a large intellectual problem inherent in the design of the Human Genome Project. It would incidentally also dedicate a large pool of resources to population geneticists, as the Human Genome Project had already accomplished for medical geneticists. Given the scientific merit of a diversity project, the question remained concerning how to convince the

public that it was indeed interesting, doable, and valuable. This was the concentrated focus of HGDP efforts, for it imagined researchers' primary obstacles to be technological, like those of the Human Genome Project. Unfortunately there was a different set of issues the HGDP was unprepared to address, namely, those associated with indigenous property rights.

Through the 1980s public opinion in the United States had come around to acknowledging the ways manifest destiny, unbridled capitalism, and science had all worked to the disadvantage of indigenous peoples. This culminated in the passage of the Native American Graves Protection and Repatriation Act in 1990, which effectively said that the cultural and biological materials that had been collected over the course of the previous two centuries were not the property of the museums that housed them but belonged to the Native American tribes from which they had been taken. Most important, it acknowledged that the scientific value and meaning of old Indian bones would be weighed against and perhaps be superseded by their nonscientific value and meanings. This was clearly not an ideal intellectual and political climate in which to be proposing industrial-scale collection of Native blood.

JUSTIFICATION AND UNJUSTIFICATION

The initial justification for the HGDP was in fact the prime interest of its organizers, namely, human microevolution. Questions would be posed about the relatedness and historical descent of populations, specifically "to see if, for example, the Irish are more closely related to the Spaniards or to the Swedes" (Morrison Institute for Population and Resource Studies 2011). Unfortunately the techniques available to make those assessments were sensitive to migration, population size, genetic markers chosen, and other variables that often made the results unstable and unreliable. Further, the statistical analyses required to reconstruct the histories often relied on unrealistic assumptions about the composition of those populations, a mythology of genetic purity. Thus each of their ostensible target populations is "isolated and has only rarely—if ever—intermixed with its neighbors" (Roberts 1991b, 1614).

The apparent ahistoricity at the center of the HGDP's scientific program was reinforced by the ease with which researchers elided indigenous peoples of the present and prehistoric ancestors of the past. Thus the targeted populations were represented as affording a "unique glimpse into the gene pool of our ancestors who lived thousands of years ago," and it was only through them "that we can hope to reconstruct the history of the human past" (Roberts 1991b, 1614). Of course it was far from clear just which aspects of "our" ancestors the Khoisan of the Kalahari Desert might be expected to elucidate. This apparent naïveté about global history on the part of the scientists proposing the project suggested to the anthropologist Alan Swedlund that the HGDP was basically twenty-first-century technology being used in a nineteenth-century intellectual framework (Lewin 1993). Additionally there had always been ideological baggage attached to the collection of genetic samples—unquestioned assumptions of genetic purity, Cold War interests in assessing the background rates of mutation of isolated peoples as a way to compare them with mutation rates due to radioactive fallout, and so on—all of which would soon begin to surface (Ventura Santos 2002; Reardon and TallBear 2012).

Further, different peoples have their own ideas about who they are and where they came from. If the primary goal of the HGDP was (whether intentionally or not) to undermine their traditional origin narratives, then it seemed unlikely that they would want to participate if that knowledge were to be communicated to them. This point later became an issue when the Havasupai sued Arizona State University after researchers not affiliated with the HGDP took their blood without indicating that it would be used to study prehistory. The case was settled out of court in 2010 (Marks 2010).

The second and concurrent justification for the project was familiar as the "salvage anthropology" of a century earlier. Various factors, ranging from genocide to intermarriage and urban assimilation, were contributing to the loss of cultural knowledge and diversity. Where the science of a previous century used it as a call for emergency ethnography, the science of the modern century used it as a call for emergency bloodletting. Thus the headline of *Science*'s first news piece on the HGDP breathlessly told readers of "vanishing peoples" who were "rapidly disappearing" (Roberts 1991b, 1614). Demography often told a different story, however, which again suggested an extraordinary degree of naïveté within the HGDP about the complex relationship between genetics and identity formation or ethnogenesis (Moore 1994). On the contrary, for populations that might indeed be on the threshold of extirpation, it seemed awfully callous and cynical to chase them down with empty syringes, hoping for a vial of blood before they expired (Liloqula 1996).

Concurrently ethnographers noted stories arising among people in diverse communities about white people who were coming to steal their blood. This was a mythological reflection to some extent of economic and political relations (Scheper-Hughes 1996), but that indeed was more or less what the HGDP was actually proposing to do. The powerful image of the bloodthirsty vampire geneticist began to spread among indigenous communities, and an exhibit at the Musée de l'Homme in Paris

went so far as to depict how indigenous peoples were representing the geneticists.

The third justification involved the production of biomedical knowledge, which had been a charm for the Human Genome Project. The first flurry of publicity for the HGDP had either ignored or downplayed biomedical results. Thus Jared M. Diamond (1991, 567), in *Nature*, wrote simply, "We could understand our differing genetic susceptibility to many diseases." *Science*'s third write-up (Roberts 1992b, 1204) identified twin goals for the HGDP: "to survey human biodiversity" and "reconstruct human history." But the project's goals did not resonate particularly strongly with the very people they were hoping to bleed, which was becoming frustrating: "Any sensible person can see this is important research," groaned Cavalli-Sforza (Gutin 1994, 72). The HGDP increasingly began to invoke hypothetical medical benefits as a further reason for undertaking it (Weiss, Kidd, and Kidd 1992; Kidd, Kidd, and Weiss 1993). In its summary document from a 1993 meeting in Sardinia, the HGDP avowed that its research "will increase the likelihood of being able to develop more effective ways of treating or preventing many diseases and may have direct practical consequences in terms of the provision of health care resources" and threw in "the inheritance of disease, the development of cancer and the processes of ageing" for good measure (Morrison Institute for Population and Resource Studies 1999). *Science*'s fourth write-up mentioned "the genetic basis of disease susceptibility" up front and even specified diabetes in Native Americans as a possible target (Kahn 1994, 720).

It was quickly pointed out, however, that the HGDP was structured around collecting genotypes but had no plans for the systematic collection of medical histories to associate with those genotypes, so any medically relevant information that it might produce would effectively be serendipitous. And because most of the gross disparities in health care are rooted in economic and political difference rather than in genetic difference, this would also seem a weak reason for undertaking the HGDP.

The fourth justification the HGDP employed was that it would help combat racism (Cavalli-Sforza 1994). This was problematic, however, in three ways. First, racism is a political act and tangential to genetics. What the HGDP might address is the absence of large natural divisions in the human gene pool, that is to say, the ontology of race. But the existence or not of race is as irrelevant to the politics of racism as the existence or not of God was to the Hundred Years' War; the injustice is no less real for being rooted in imaginary categories. Second, normative human genetics since the 1970s had consistently concluded that race was not a genetic category in the human species. Consequently that knowledge fell into the category of "already known" and thus was hardly an argument for undertaking the HGDP. And third, the HGDP was paradoxically reifying race in its own scientific publications, notably concluding in one study that "ancestral Europeans are estimated to be an admixture of 65% ancestral Chinese and 35% ancestral Africans" (Bowcock et al. 1991, 840; see also Reardon 2004).

ETHICAL QUESTIONS

The HGDP's scope and aggressive publicity campaign called attention to practices that had been proceeding on a small scale for decades but which had never been interrogated (Lock 1994; Baird 1995). Although many researchers had good long-term relationships with Native peoples, there was a unilateral understanding that one could say anything to acquire the sample. Once it was out of the subject's body, it was the property of the researchers, who could use it any way they pleased and trade it to other labs in exchange for coauthorships on scientific papers with no recognized responsibilities to the person it came from. In many cases the identity of the person was not even acknowledged, for the sample was scientifically valuable only as a biological synecdoche of the population or ethnic group of which the person was a member. Suddenly under scrutiny, these practices seemed outdated and colonialist (Cunningham 1997).

The HGDP strained the framework of contemporary bioethics, which emphasized issues of autonomy, privacy, beneficence, and justice mediated by the responsibility of the researcher to obtain voluntary informed consent from subjects (Knoppers and Chadwick 1994). The HGDP inadvertently raised more complex questions. To what extent can consent be considered to be "informed" if the subjects do not share the same ideas as the researcher about the most fundamental aspects of the research, such as cells, descent, blood, health, relatedness, origins, and DNA? Is the model that holds the individual adult citizen as autonomous appropriate for research on peoples who do not share those views of individual freedom, agency, and responsibility? What long-term obligations to participating communities may be incurred through the long-term preservation and storage of their genetic materials by scientists? Because membership in human groups is fluid, what entities is a participant in a genetic study considered to represent, and is the consent appropriate for the group being studied? How can the intellectual and property rights of indigenous peoples be safeguarded (Rose 1999; Schüklenk 1999; Winickoff 2003)?

Cavalli-Sforza was himself regarded a bit skeptically by biomedical researchers who had good relationships with indigenous peoples and with whom he had developed a reputation for trying to procure genetic samples largely untethered from human relationships and

obligations (Anderson 2008). Cavalli-Sforza told a story about his own collection of samples to *Time* magazine, temporarily exchanging the image of ethically conscious scientist for that of swashbuckler, when "potential donors were often afraid to cooperate, or raised religious taboos" (Subramanian 1995, 54). On one occasion when Cavalli-Sforza was taking blood from schoolchildren in a rural region of the Central African Republic, he was confronted by an angry farmer brandishing an ax. Recalls the scientist: "I remember him saying, 'If you take the blood of the children, I'll take yours.' He was worried that we might want to do some magic with the blood" (Subramanian 1995, 54). Of course the work had been done many years earlier under a different regime of ethical oversight, but beyond the glaring questions of autonomy and consent, one need hardly even ask what benefit the African farmer might have received from the science that disturbed him so profoundly. These were questions that were indeed finally being asked, and it was becoming clear that the scientist-subject relationship that had obtained for population genetics in the 1960s was no longer considered adequate.

More important, the DNA samples were beginning to have financial value, and their collection was quickly associated in Native communities with "biocolonialism" and "biopiracy," in which local knowledge and resources were taken and commodified by nations or corporations without sharing the profits with the local people (Harry 2009). The patenting of human cell lines had begun, and the HGDP was unprepared to speak authoritatively on the matter except to say that they would not do it. In 1995, however, a patent was issued to the National Institutes of Health for a cell line derived from a man of the Hagahai tribe in Papua New Guinea (Lock and Nguyen 2010). Although it was not affiliated with the HGDP, it clearly illustrated that the problem existed: the genomes that the HGDP planned to collect were worth something, the precedents seemed to be aligning against the idea of patients or subjects as partners, and the HGDP seemed unwilling or unable to assume a role of leadership in the relevant science-and-society discussions.

Whereas the HGDP's primary goal would necessarily undermine traditional Native beliefs about origins, its public documents invariably articulated a concern to "respect" those very beliefs. The irreconcilability of those aims notwithstanding, the fact remains that the very substances the HGDP sought are often among the most sacred, powerful, and magical cultural substances, and the HGDP seemed to be paying remarkably little attention to the responsibilities thereby incurred.

One area in which the HGDP took a proactive role was in developing a concept of "group consent" (Greely 1997). Because population geneticists were interested in people primarily as representatives of their groups, the HGDP proposed adding a second tier of consent. In addition to individuals' opting in or out, the groups themselves could opt in or out. Eric T. Juengst (1998), however, argued that this would likely raise more problems than it would solve. A blue-ribbon panel of the National Research Council in 1997 agreed that studying the breadth and structure of the human gene pool was indeed a meritorious scientific project but recommended against funding the HGDP, citing outstanding and unaddressed social and bioethical issues (Greely 2001).

LEGACY

In many ways the issues broached reluctantly by the HGDP have never been resolved. How does one acquire the voluntary informed consent of someone who does not share the same understanding of life, death, heredity, cells, illness, health, or genes? To what extent does an onus fall upon the scientist to communicate the scientific ideas intelligibly? Is group consent legitimate/necessary/allowable in human subject protection regimes? What rights do indigenous peoples have vis-à-vis science? What is an appropriate profit-sharing model in a free-market genetics economy (Greely 1998)?

Laurie Anne Whitt (1999) notes that an indicator of just how low a priority these questions held in science at the time is that while the bioethical issues were being put forward in response to the HGDP publicly in the early 1990s, the National Science Foundation's physical anthropology directorate actually set up a program for pilot HGDP grants—which seems an unusual step in the midst of a public debate over its ethical status. Its organizational meetings, which had been funded by public and private moneys, had focused almost entirely on methodological and technological issues—who should be targeted, whether to structure the sampling by geography (arbitrary grids drawn on a map) or by ethnicity (presupposing the naturalness of human groups and membership within them), how many samples would be needed, and so forth (Roberts 1991a, 1991b)—and the social and ethical issues were treated reactively. The organizers were not interested in establishing the conditions under which they would be procuring the cells, intending instead to outsource that dirty work to anthropologists or to "networks of reliable researchers … in each region to take responsibility for this" (Morrison Institute for Population and Resource Studies 1999). Indeed the initial reaction of the HGDP to questions about the collection of the actual specimens based on interacting with actual people was to trivialize, dismiss, and demonize its interrogators for ostensibly politicizing what they had imagined to be an apolitical conversation

about the global collection of blood from indigenous peoples (Gutin 1994).

The cell lines established by the HGDP are now in the care of the Center for the Study of Human Polymorphisms in France (Cann et al. 2002). Diverse cell lines, including those, are available from the Coriell Institute for Medical Research (2009), from which, for example, cells derived from a Karitiana woman from Brazil or a Yoruba man from Nigeria can be purchased for $85.

The commodification issue is particularly vexing. In 2005 the Genographic Project was begun with largely the same goals as the HGDP but with one significant difference: it had private funding in place from the outset. Again generating media interest through popular books and television shows, the Genographic Project was also formulated without bioethical input, and questions were quickly raised about it concerning basic issues of consent and identity (Harmon 2006). It also gave credence to the questions of exploitation and colonialism when it entered high-end tourism, sponsoring a "Journey of Man by Private Jet," which solicited clients to pay over $70,000 to visit remote exotic peoples and have their DNA tested to establish fictive genetic kinship with the local people. Potential clients were assured that their trip would be not only luxurious but also without obligation: "By joining this expedition, you will automatically support efforts to enhance the conditions of the places and peoples we visit—there is no further commitment necessary on your part. Our expedition will provide supplies to medical clinics and schools, as well as contribute funds for essential projects that many people depend on" (TCS and Starquest Expeditions 2009).

SEE ALSO *Genetic Testing and Screening; Genetics and Human Self-Understanding; Genetics and Racial Minorities; Global Health Inequalities and Inequities; Human Genome Project; Informed Consent: III. Consent Issues in Human Research; Patenting Organisms and Basic Research; Race and Racism*

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HUMAN GENOME PROJECT

Without acknowledging reliance on radiographic measurements and structural inferences from Rosalind Franklin and Maurice Wilkins, on February 28, 1953, James D. Watson and Francis H. Crick formally announced the structure of DNA, recognizing at once the potential of the double helical structure for storing and replicating genetic information. A month later on March 19, 1953 Crick penned in a seven-page handwritten letter to his twelve-year-old son away at boarding school: "We have built a model for the structure of des-oxy-ribose-nucleic acid, called DNA for short. In other words, we think we have found the basic copying mechanism by which life comes from life" (Watson and Crick 1953; Sivakumaran 2013). In the wake of the rediscovery of Gregor Mendel's basic laws of heredity by Hugo de Vries, Carl Correns, and Erich von Tschermak-Seysenegg in the early 1900s (Roberts 1929), this announcement fueled a spate of groundbreaking research in molecular biology, bioinformatics, and ethics (Juengst 1996; McCain 2002; Collins et al. 2003; Koski 2005; Gannet 2008; US Department of Energy Genome Research Programs 2008; National Human Genome Research Institute 2013).

THE HUMAN GENOME PROJECT: A SELECTED HISTORICAL BACKDROP

Stepping stones toward the Human Genome Project (HGP) included rapid achievements. Frederick Sanger sequenced the first protein (bovine insulin) in 1952 (Sanger 1952), and four years later Arthur Kornberg discovered the polymerase enzyme that synthesizes DNA in *E. coli* bacteria (Kornberg, Lehman, Simms 1956). In 1957 Francis Crick and George Gamov articulated the "Central Dogma" of molecular biology (Crick 1958). Their "sequence hypothesis" posited that the DNA sequence specifies the amino acid sequence in a protein. They also suggested that genetic information flows only in one direction, from DNA to messenger RNA to protein, the central concept of the central dogma. In 1961 the